

SEE/HEAR

A QUARTERLY NEWSLETTER ABOUT VISUAL IMPAIRMENTS AND DEAFBLINDNESS FOR FAMILIES AND PROFESSIONALS
A collaborative effort of the Texas School for the Blind and Visually Impaired and Texas Commission for the Blind

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To Begin With...

we are looking at personal issues in this month's *SEE/HEAR*. We put articles about toileting or sexuality in the first three sections. I hope you find some helpful information about these subjects we often avoid. There is lots of other interesting reading as well. Take a look at the classified ads for training opportunities. We hope to see many of you in Austin in February for the 2003 Texas Symposium on Deafblindness.

Our new editorial staff is now on board, and looking forward to bringing you a publication you can use. Please contact us with comments or ideas.

The Ride of Her Life

By Kathy Fisher, Parent, Vanderbilt, Texas

Wearing a riding helmet and belt, my daughter Megan is grinning ear to ear. She's prepared for one of her favorite activities, riding a horse. Since the age of three weeks, Megan has spent much of her time in physical and occupational therapy. One of the most beneficial types of therapy she has experienced is hippotherapy, also known as riding therapy. Many people think of horse riding therapy as simply a child riding around an arena on horseback. For my daughter Megan, a fourteen-year-old multi-handicapped child with low muscle tone, riding therapy has changed her life.

Riding for Megan began at age three. Not able to control her upper body or hold up her head, she resembled a rag doll. She required an adult to ride behind her. This back-rider was responsible for keeping Megan's body in an upright position. Riding was physically hard on her and as a result, she cried for a whole year. Thankfully we didn't become discouraged. We learned progress took time.

Slowly she gained control of her head and neck muscles and was able to sit up by herself. This was when she truly started to enjoy riding. Her daddy would sing "Happy Trails" to her on the way to the riding center. She would get excited in anticipation. Once she saw the horses, she'd wave her hands in the air with a smile covering her whole face. I, too, was excited. Sitting up meant she could finally sit in a high chair and shopping cart. I wouldn't need someone to accompany me to the store anymore!

Megan learned to pat the horse twice to make it move, which reinforced cause and effect. Once she learned this concept, other learning could take place.

Crossing midline happens when a child's arm crosses from one side of their body to the other. Parents are told how important crossing midline is in their child's development. Although this was attempted at home and at school, Megan hadn't mastered it yet. She worked on this skill while on the horse, and for some reason, would try harder. She eventually learned to cross midline by taking a large plastic ring in one hand, learned to transfer it to the other hand, and give the ring to a side-walker. These steps were repeated until Megan could cross midline independently. This meant that she could play independently with toys, switch from one hand to the other, and interact with people by giving them her toys.

As Megan gained more upper body strength, she rode backwards on the horse. I could tell she didn't like riding this way; she'd fuss! The physical therapist explained riding backwards worked her weak arm and shoulder muscles more than riding in a forward position. As long as the side-walkers talked to her while she rode, Megan tolerated the backwards riding.

Since Megan sat up so well, I wondered if it was foolish to think she could learn to crawl. She was placed in a 4-point position (hands and knees) on the horse. With the horse standing still, Megan would actually do push-ups on its back, with her legs being held in place by side-walkers. This motion was repeated on the floor at home with me moving Megan's arms. When this was well tolerated, Megan was again placed in a 4-point position on the horse's back. The horse was slowly moved forward two or three steps and stopped. Megan felt the left then right movement of her body on the horse. She learned to crawl shortly after beginning this activity!

During this time I noticed more normalization of muscle tone. Working on correct posture, she became more aware of her body in space. Specialists had told us that Megan would never sit up, crawl, or walk. Following work on weight bearing, Megan could stand holding on to something, but would stiffen her legs and wouldn't move them. Doctors still discouraged us from believing she would walk saying, if she had not walked

by age five, it would never happen. At age eight, after a few sessions of riding Buster, a horse with a definite left to right hip movement, Megan took her first step. This happened on Mother's Day, 1996. What a miraculous gift!

Megan loves the sights and sounds she experiences while riding in an open arena. Although she doesn't talk, she vocalizes more while riding. She doesn't realize she's actually receiving therapy and even has a physical therapist walking behind her. Megan has cortical visual impairment. With each therapy session, her head is held more upright instead of the usual downward placement or the head tilted upward looking at the sky. She's actually looking at what she's doing.

We are fortunate that the Victoria Riding Therapy Center has a sensory trail. Sights, sounds, and tactile stimulation are the primary objectives of this path. Megan particularly likes the "clopping" noise made when the horse walks across the wooden bridge. She often laughs as she feels the movement of the horse going up and down a small hill. She doesn't realize she's working to control her upper body while keeping her balance. She just knows she loves to ride.

Megan enjoys taking a ride.

Eleven years later, Megan is walking with a walker. She is still riding, working primarily on posture and hip movement. The excitement she shows as she rides is worth all the hard work and time spent in riding therapy. She has greatly benefited from hippotherapy. Teamed with traditional physical therapy, it's amazing to see the accomplishments that can be made. I highly recommend this type of therapy for any child with special needs.

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One Giant Leap for 5-Year-Old Meredith

By Sarah Barnes

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Special to the Austin American-Statesman, Thursday, July 25, 2002

My daughters, Meredith and Caroline, rode a wagon in our neighborhood July Fourth parade this year. As my husband, Jim pulled them down the street, my thoughts were already turned to next year and how I hoped both of them would walk in the parade. For Caroline, who will be 2 next summer, that will be easy. But with every year that passes, my dream of seeing my 5-year-old walk fades just a little. Meredith has a rare brain anomaly resulting in weak motor skills. When she was 1, she sat up. At 2, she crawled. At 3 and 4, she began to cruise along the furniture and use a walker. As parents who've watched her struggle, Jim and I learned to appreciate every inch of progress, not wanting to set a goal that, we fear, can't be reached.

I am happy to report that one should never say "never" to a determined 5-year-old.

A few days after the parade, we were getting Meredith ready for bed, and I had just come into her bedroom with her toothbrush. Meredith and Jim were sitting on the floor. At that moment, for reasons we'll never know, Meredith decided to get up on one knee followed by the other knee. Then she put her hands out in front of her on the floor and began to rise from a squatting position into a standing one. She tries this often, but never makes it to the stand. On this night – July 7 – she did. Stunned, but ready for anything, Jim and I instinctively got in front of her and held out our arms.

“Come on Meredith, you can do it. Take a step,” I said.

She smiled big and paused to let her muscles consider what her brain was telling them to do. Then the moment that will forever be etched into our minds happened. Meredith put her right foot forward. Then her left. Then her right. Then, for the first time, our little girl walked all the way into our arms and gave us a hug.

“Oh my God,” I whispered to Jim. “She’s walking.”

“Meredith,” I said clutching her tightly, “we’re so proud of you.”

But Meredith wasn't interested in savoring the moment. She was on the go. All over the house. There were no leg braces or walker wheels to guide her, just her own flesh and blood legs. Jim and I were still in disbelief as we shadowed her all the way down the hall, watching her take confident quick steps as if she had done it for years. There was only one thing to do.

“I’m getting the video camera,” Jim said. When your child does not show any interest in walking on her own for five years and suddenly just does it, well, you need proof. In seconds Jim came back to her room, camera pressed to his eye, finger on play.

Meredith did not disappoint us. She walked steadily from her bedroom to our bedroom to her sister's bedroom and down the hall again. I hurried back to our bedroom to call my mom.

“Mom, guess what? Meredith is w-a-l-k-i-n-g.”

“Oh my God, are you kidding?”

“No, I swear,” I said. “Come over right now.”

“I’m coming over,” she said.

“Hurry,” I said, “before she stops.”

In a few minutes, Mom and her husband, Neal, arrived and headed toward the hall where, at the opposite end, Meredith stood – quite literally contemplating her next step.

“Look Meredith, it’s Grandma Missy. Can you come give her a hug?”

Meredith smiled and looked at my mother, who had her arms extended. With little hesitation, she walked ahead with determined steps. Mom covered her mouth when she saw the first steps and said, “I think I’m going to cry.”

Meredith spent the entire next hour walking all over the house. She seemed so excited to be tall for a change, seeing things at a different level without a walker. She finally took a rest about 10:15, and her grandparents went home. Jim and I were still savoring the moment when he announced he had a surprise for me. I couldn't imagine an evening filled with any more magic, but he emerged with a tiny sack.

"Open your hand," he said.

Cupping his hand under mine, he tipped the sack and a tiny pair of gold shoes slid gently into my palm. "I've been waiting two years to give this to you – on the day when Meredith walked."

The moment took my breath away as I looked at the little charm – a tangible symbol of a day Jim and I have been dreaming about since the doctor told us he didn't know if our little girl would ever walk. Someday, I hope that Meredith will ask me to tell the story behind each of the charms on my bracelet. I'll start with the little gold shoes.

Sarah Barnes writes occasionally about the joys and challenges of raising a child with special needs. You may contact her at <adifferentroad@aol.com>

Toileting Tips for Determined Parents!

By Leslie Fansler, Parent, Amarillo, Texas

When our son, Preston, who is Deafblind, was three years old he entered into the public school system's early childhood program designed for children with disabilities. We were blessed by having the most fantastic teacher in the world! Within a few months Preston was up, walking, and going everywhere. The teacher suggested that we start trying to toilet train him. I was skeptical, but we gave it a try. Here are some things we tried that worked, didn't work, and things we have learned.

First, we decided on a symbol for toileting for Preston's calendar box (I do not know why we didn't think about a symbol Preston would have chosen). We used an empty toilet paper roll, which was not really meaningful, as Preston didn't realize that an empty toilet paper roll is even tied to toileting! We were not having much success getting him to understand the whole toileting concept and sitting on the toilet was extremely boring, even when we piled toys all around it. He loved to play with balloons that were not quite fully inflated. He would sit for a long time and just play with a balloon, so we started giving him one to play with while he sat on the toilet. Bingo! It didn't take us long to figure out that a balloon was the BEST symbol for toilet for Preston. We began using it in his calendar box and he started looking forward to going into the bathroom to play with a balloon. We made sure that he never got to play with a balloon anywhere else, only in the bathroom. Preston began to have some success and we began to believe that he could be an independent toiler!

The next idea we came up with was a tactile path to the bathroom. I purchased heavy duty, tactically interesting material at an upholstery shop and sewed it together to form a long narrow pathway. We used this pathway to help Preston establish a route to the bathroom. At home we tacked it up on the walls, in the hall that approached our bathroom door. Preston would run his hand along the path as he walked to bathroom. At school they laid the pathway on the floor and he walked on it to go to the bathroom. He began to pair the pathway, the bathroom and playing with a balloon all together and decided that this was a fun routine. We could take the pathway with us anywhere so he always had a clearly marked route to a bathroom. This was extremely helpful when he was young and routes were confusing to him.

During this process his whole team, at home and at school, continued to work on his dressing skills so that he was able to handle his clothing in the bathroom. He still, even today, is unable to independently handle the fasteners on his pants, but I am sure that he will eventually master those skills.

TSBVI's Deafblind Outreach Team had spent time teaching us how to fade prompts so that Preston would not become a prompt junky. We used those techniques with the toileting routine. First we took Preston to the calendar box, where a balloon signaled the toileting routine, then down his pathway to the bathroom, on a schedule. Next we began to take him to his calendar box and to the beginning of his pathway. Then we took him only to the calendar box and he found the pathway on his own. Lastly, we just reminded him to go to the bathroom. Finally he reached a stage where we did not have to tell him; he just went to the bathroom on his own, without a prompt from us, or the calendar box. We no longer have to use the pathway or a balloon. Hey, we have made great progress!

Recently he was playing outside on the trampoline. He got off the trampoline, came across the backyard, in the back door, through the house and went to the bathroom, completely on his own!

Needless to say, we are extremely pleased to report that Preston is now toilet trained! In known environments he handles toileting himself. Wiping after a bowel movement is still an area we are working on. We are now teaching him to wipe every time he sits on the toilet, as he does not seem to understand that sometimes he needs to wipe, and sometimes he doesn't. We think it will be easier if wiping is always part of the routine.

These are things we have learned from Preston and this process. When you decide to toilet train a low-functioning child, be prepared to commit to at least ten years and really think through the toileting routine before you start. We made mistakes that probably added time to the process and confused Preston. It took about ten years to get Preston to where he is today, so just be prepared to make that long-term commitment. Many families try for a year or two then decide to wait until their child is a little older and try again. I think this is very confusing to kids. First I am expected to sit on the toilet, then I am not expected to and then at some magical date in time I am expected to again. We never quit trying after we got started, even though we were often very discouraged.

I do not believe in using pull-up type disposable underwear. It sends mixed messages to a child with cognitive difficulties. I am supposed to try and get to the bathroom, but if I don't make it that is all right because these pull-ups are similar to a diaper. We put Preston in underwear and he has stayed in underwear. There have been times when underwear have been a REAL HASSLE and pull-ups would have been MUCH easier, but Preston has ALWAYS known that it is not all right to wet his underwear.

Another thing we learned is that Preston loves to play in the water. When he soiled or wet himself I would immediately put him in the shower to clean him up. One of his teachers pointed out that this was a great reward for having a toileting accident. Now if he has an accident he has to clean himself up using baby wipes. That is not near as much fun for him. Pay attention to rewards and consequences during toilet training.

Toilet training a low-functioning child is not to be taken lightly, and is not for the fainthearted! It takes time, a strong commitment, a team effort, and great patience. A little stubbornness on the part of the adults helps immensely! I have had many parents ask me how we accomplished this, as they have not been able to and their older child is still in diapers. I always ask them to think about their child as an adult. Those of us who have low-functioning children will eventually have to think about adult placement. Preston's adult placement will be greatly enhanced because he is an independent toileter. It was definitely worth the commitment and effort!

Making the Most of the Holiday Season

By David Wiley, Transition Specialist, Texas Deafblind Outreach

Now that we are in the midst of the “holiday season”, it is a good time to reflect on what makes holidays so special to us: traditions; rituals; helping others; giving and receiving; friends and family. When someone is visually impaired or deafblind, it is possible that many of the things that make holidays so special can be missed, or difficult to fully appreciate. It is important to consider how we make things like decorations, music, pageants, celebrations, parties, and gatherings meaningful to young people with sensory impairments. Some years ago I saw an article in *Talking Sense* (Winter, 1995), a publication of the National Deafblind and Rubella Association in the UK, that recounted the ways many people who are deafblind joined in holiday traditions.

HOLIDAY TRADITIONS IN THE UK

That article recounts the story of Janet, whose family has a special Christmas calendar to which Janet attached a new picture or object symbol on each day leading up to the Christmas symbol which is already located on the 25th. Janet also participates in gathering presents to distribute to family members, and joins in cooking the Christmas dinner, and setting the table. Though her mother feels Janet doesn't fully understand the true meaning of Christmas, she enjoys the happy family occasion, and looks forward to the tradition the family has established.

There is also the story of Jacqueline, who especially likes tree lights and brightly colored decorations. For this reason, her family gets her Christmas presents that produce light. The article also mentions another group of people who are deafblind, and live together in a group home, that all receive presents involving light, vibration, aromas, or sweets to make getting gifts enjoyable.

Richard participates in making greeting cards to signify the holidays. He also participates in the shopping, and gets to choose decorations for his room, as well as helping with the Christmas tree. Another group reports punching cloves into oranges to make pomanders for decorations, and filling the home with scents only used during the holidays. They decorate in meaningful ways. Tinsel and bells are examples of decorations that can be appreciated tactually. Participating in both decorating and packing the decorations away after the season provide clear ways to show the beginning and ending of the holiday time.

WHAT DOES YOUR FAMILY DO?

I would like to find out what your family does for the holidays to make them meaningful and enjoyable for your child with sensory impairments. Send me your family traditions and activities for Halloween, Thanksgiving, Hanukkah, Christmas, or New Years Day. Include family traditions, decorations, and meaningful gifts. Give me some information about your child, and how you have learned to include him or her. If I get plenty of responses, next year I will put together an article on holiday celebrations, Texas style.

So, as you make your way through the holidays, please take time write down what you and your family do. Sharing your ideas is so helpful for other families. Send your thoughts to: David Wiley; Texas Deafblind Outreach; 1100 W. 45th Street; Austin, TX 78759. You may e-mail me at <davidwiley@tsbvi.edu>.

Don't forget to write. And Happy Holidays.

My Story: Choices for Students with Low Vision

By Dawn Adams, CTVI, COMS, Mesquite ISD

“She is blind and will always be blind; there is no use in hoping for anything better.” These were the words spoken to my dad just days after the custody papers had been finalized. A single man of age 55, who owned a night club in Houston noticed that one of his “regulars” had just given birth to a baby girl. He had heard that she did not want the baby and could not raise her. With his own children grown and married with children of their own, it did not look to be the most convenient time to begin raising another child. Looking past the circumstances and focusing on his love for the baby, he decided to find out if he could adopt me. Mother signed over her parental rights to him and that is where my story begins.

Dad noticed I was not like other babies he had been around. For one, I was very still. I did not reach out for objects or people, and I was quiet. At times he would notice that I would turn my head toward sounds, but that was it. The doctor informed dad that I was blind, not partially sighted, but blind.

A magazine article was given to dad that told the story of how a blind baby had been carried upside down for short periods of time. Something about the blood carrying nourishment to the nerves of the eyes caused the child to see. Believing that it was worth a try, dad began carrying me upside down for short periods of time. When I became tired, I would pull and he would carry me the usual way. One day as he was carrying me around the pool table in the club, he noticed that I turned my head toward the light above the table and reached out for it. From then on I began paying attention to other objects. There was no doubt in dad’s mind that I was able to see something. At 18 months I began walking, quite a bit later than sighted children. At one eye-doctor appointment I was given some picture cards to read. I correctly named nearly every picture! This was the same eye specialist who told dad that I was blind and would always be that way. He was absolutely amazed!

Now, I don’t know if I really believe that being carried upside down caused me to see or not, but I do know that I believe in miracles. Little by little my vision did improve and I learned to use the vision efficiently.

As a kindergartener I began receiving services as a student with a visual impairment. When I was five I went to the low vision clinic with my dad and vision teacher. The doctor gave me my first telescope. With it I could see things so much more clearly. I could see people and objects that were far away. Dad and I would play “I Spy” together. He would tell me to find the “blue sign” or the “airplane in the sky.” Without my telescope, I could see the general location of objects and people at a distance, but with it, I could see details. It was not until I used this telescope that I realized it was possible for people to see the individual leaves on a tree, and I could see that bird way up there too! Of course, the primary function of the telescope was eventually for me to learn to read the chalkboard in school. I will always be thankful to my dad for the support he gave me.

Through the years I have had various types of monoculars (telescopes). I used a hand-held one until fifth grade. Then I received my first pair of glasses with a mounted telescope over the right eye. Since I have no central vision in my left eye, I need to use the telescope with my right eye. It is difficult to pick up and put down the telescope while trying to copy information off of the board. I really liked the new glasses because they allowed me to have my hands free for turning pages or writing. Next, I was fitted with a similar device, but this time the telescope was much smaller and much more cosmetically appealing. Also, it could easily be used for distance as well as near tasks. I could read my papers and books with it, or I could read the chalkboard. The use of large print books helped me not to have to constantly switch back and forth between near and distance focusing. I used large print to read and kept the glasses focused for distance tasks most of the time. Eventually I was fitted with a pair of Ocutechs which can be used for driving. My Ocutech has a telescope (very small) above the right lens. When I want to verify something I see with my vision, I very quickly look into the telescope to see it. My vision is corrected from 20/200 to 20/30 with these glasses.

The development of efficient use of my residual vision has been a key factor in my education. I was always encouraged to use my vision, and I learned how to use it effectively. I was also not embarrassed about looking different because of my special glasses or telescopes. As early as kindergarten, dad reminded me that it was more important for me to be able to see than to be worried about what others would think. In fact, some of my classmates were quite interested in my vision devices, and it was fun to show them how the various devices worked (without letting them play with them).

My senior year I also received training in Orientation and Mobility so that I could learn to cross streets. This included using a cane for identification purposes. I used my vision in conjunction with the cane. I have also used programs such as ZoomText to enlarge print on a computer screen. Now, however, I simply use the options in the control panel of the Windows ME Software. Having efficient use of my vision has enabled me to participate in high school athletics and driving, in addition to seeing things that I might not have otherwise been able to notice, such as seeing a bird in a tree, locating things in a cluttered background, etc. It now allows me to use current technology and travel independently. My primary learning mode is through vision; that is, I am a visual learner. So the use of vision has been essential to my education.

Today, as a teacher of students with visual impairments and an Orientation and Mobility Specialist, I still use low vision devices in my daily routines. Whether it is completing ARD paperwork, progress reports, reading for my graduate courses, or cooking a meal for me and my husband, a CCTV is used much of the time. I also have reading glasses which help me when a CCTV is not available. In addition to my reading glasses and driving glasses, I use a hand-held telescope to read the list of goods on the aisles in the grocery store or read street signs when walking. My purse is a “tool bag” for my three low vision devices. I have a device to help me accommodate to any visual task.

While professionals may not all agree on what is best for students with low vision, it is clear that there are obvious advantages to using residual vision. Ultimately each person must decide whether to learn to use his or her vision efficiently, if possible, or to become a tactual learner. One way of learning is not necessarily better than another. It simply depends on the person. Each person is different, and in our field we are to address the individual needs and strengths of our students. We cannot say what is true for one is always true for the other. “My story” is about what has worked, and is still working, for me. My husband and I both are visually impaired. I’m glad we’ve had choices and opportunities to learn to use our vision. It has been said that “being visually impaired is hard work.” While it is hard, it is not impossible to overcome the challenges.

Strategies for Minimizing the Risk of Sexual Abuse

by Maurice Belote, Project Coordinator, California Deaf-Blind Services

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The incidence of sexual abuse among persons with disabilities is staggeringly high, and yet abuse prevention is rarely addressed in school programs for these individuals. Teaching children who have multiple disabilities including deaf-blindness often requires creativity and the ability to adapt and modify existing materials and programs. When teaching abuse prevention, it may not be adequate to simply follow the same instructional objectives used among children without disabilities—don’t talk to strangers, run away and tell a safe person if someone is trying to hurt you, etc. For a child who is deaf-blind, intervention will need to encompass many curricular domains, including the areas of communication, self-help, and social skills. The following strategies may be useful in creating an instructional program to address prevention of abuse and exploitation.

START YOUNG.

Issues of sexuality begin at an early age, and instruction during these early years creates a foundation onto which everything else can be built. Some of the early skill areas that will assist in abuse prevention instructional activities include curiosity about the bodies of other people (children and adults), names and function of body parts, and public restroom behavior. In addition, this is the time to make children feel comfortable about talking to their parents or caregivers about personal issues. This comfort level—established at an early age—will be very helpful as the child passes through adolescence and young adulthood. Despite what we may think, national research consistently suggests that teenagers *want* to discuss these issues with their parents, and that adult-child communication is effective in decreasing sexual risk behaviors.

KNOW THE PEOPLE WHO INTERACT WITH YOUR CHILD.

Sadly, most abusers aren't strangers, but people who know their victims: friends of the family, neighbors, service providers, etc. If a situation doesn't feel right, trust your instincts and intervene. An Internet resource can be found at <<http://www.sexoffender.com>> that provides a database searchable by state and also a guide to Megan's Law (don't accidentally type sexoffenders—plural—or you will go to an adult material website). And while vigilance is important, there is probably no need to be overly suspicious of everyone who interacts with children. The vast majority of friends, neighbors and service providers are caring people who would never put a child's safety and well being at risk.

MAKE SURE SKILLS ARE GENERALIZED.

When teaching abuse prevention skills, use the same methods that help ensure that all skills are generalized—teach the skills in multiple locations and settings, with multiple people, and at various times of the day and night. A significant component of skill acquisition is testing to determine if the skill is truly mastered and generalized. Don't assume that a child will perform in a certain way if she or he has demonstrated the skill in a contrived setting with familiar adults. You may need to set up a situation where the child must demonstrate mastery in an unfamiliar setting with unfamiliar people.

TEACH TERMINOLOGY, INCLUDING SLANG.

It may be difficult for an individual to relay information about abuse or mistreatment if the person lacks a way to communicate this clearly. Building vocabulary regarding body parts and action words is an important step to providing the individual with a communication system that will last a lifetime. It may also be necessary to specifically address the use of slang. For example, an individual who isn't knowledgeable of widely used slang terms for genitalia and sexual acts is more vulnerable because of their lack of sophistication, even if they know the proper "medical" terms for the same things.

RESPECT PRIVACY; AND INSIST THAT OTHERS DO SO TOO.

It is important that we provide children with significant disabilities the same respect and dignity we give all people. It may be necessary to teach the concept of modesty, and be certain that this instruction respects individual family values and norms. For children who require help with daily living, issues of privacy and modesty may be complicated by situations where adults and even peers are providing assistance with physical care needs that require intimate physical contact. One way to handle this, from an early age, is to ask the person's permission before helping with intimate or invasive tasks. If requesting permission is established early and consistently, the person who is receiving help is much more likely to feel she or he is in control of their body, and in control of where they are touched and by whom they are touched.

TEACH APPROPRIATE BEHAVIORS.

We want to teach our children and students to act in the same way we expect others to when those others interact with our children. For example, we want our children to resist if other people try to touch them in inappropriate places on their bodies. This will be difficult to teach if these same children have been allowed to touch others in those same places. The goal is to establish norms, so that behaviors outside of these norms are clearly viewed as such.

PUT IT IN THE IEP.

Don't assume that goals and objectives discussed in the IEP meeting will be implemented if they are not part of the written plan. It isn't necessary to include *everything* in an IEP, but too often there is a reluctance to include items in IEPs that are out of the ordinary domains such as functional academics, gross/fine motor, communication, etc. If a particular skill is very important to you, do not accept an explanation that instruction in this skill doesn't need to be written into the IEP because it will be addressed all the time throughout the child's program. The IEP is the family's assurance that a skill will be addressed, and also provides a forum for discussing mastery towards the goal at subsequent IEP and team meetings. For service providers, IEPs provide concrete plans, and help maintain consistency between programs and staff members during times of transition or instability.

Self-Advocacy Skills: A Portfolio Approach

by Cathryn S. Krebs, TVI, Fairfax, VA

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Self advocacy is knowing what you want, what you are entitled to, and how you can effectively achieve your goals (Brinckerhoff, 1994). I think that when students with visual impairments understand their individual strengths and needs, they will be more assertive and be empowered to find or create optimal learning environments. Students with visual impairments need to be able to explain their disability in everyday language, to list their strengths and needs, to make choices about how they learn best, and to communicate effectively with their peers and teachers regarding reasonable and appropriate accommodations.

As middle school students approach high school, we expect them to be more independent. I asked the four eighth-grade students in my vision resource room to begin a self-advocacy portfolio by writing "What I Know about My Visual Impairment" and "What I Would Like to Explore." All four had self-advocacy goals in their Individualized Educational Programs (IEPs). The following are some of their questions:

- What caused my eye condition?
- Will my children have a visual impairment?
- How many people have my eye condition?
- Is there a way to prevent it?
- Do kids and adults get this?
- How much research has been done on my eye condition?
- How can I meet someone with the same visual impairment?

VISUAL IMPAIRMENT RESEARCH

During basic skills class time with the teacher of students who are visually impaired, the four students used Zoomtext (an enlarged screen reader) and JAWS (a speech synthesizer) to research online their individual situations as described in their eye reports. We also used resource books, large diagrams, a tactile model of the eye, and a conversation with an ophthalmologist. Because all four students initially had difficulty explaining their visual impairments in everyday language, they were eager to improve their awareness of their disability. One student even stayed after school to work on this project!

Several students had specific questions they needed to ask their parents or guardians. Two of the four students were comfortable talking to their parents or guardians about their visual impairment. One student, who had had radiation as an infant, wondered if the cancer might possibly recur. Another student wanted to know how functional vision was related to visual acuity measurements.

Students practiced orally explaining their visual impairments to each other and their peers and shared drafts of their explanations. Then they wrote “What I Found Out About My Visual Impairment.”

VISION VOCABULARY LISTS

From the information they had gathered, we compiled a list of specific words and definitions related to their individual impairments. Two of the four students had additional disabilities (spatial and memory problems and ADHD) that were important to understand in relationship to their visual impairments. Word lists included parts of the eye (e.g., macula, optic nerve, optic disc, retina) and other vision-related words (e.g., bilateral coloboma, congenital, cortical blindness, eccentric viewing, enucleation, null point, nystagmus, oculist, ophthalmologist, peripheral vision, prosthesis, radiation, scotoma, tumor, radiation, and visual overloading). We discussed the words on their lists individually with each student and how the word helped them to understand their functional vision.

LEARNING STRENGTHS AND NEEDS

After the research and vocabulary activities, students wrote about their learning strengths and needs. I encouraged them to talk to their peers, families, and school staff while compiling their lists. Sometimes there was negotiation if a strength or need did not seem realistic.

LETTER WRITING

Using all the information in their self-advocacy portfolios, the students wrote letters to their ninth-grade teachers describing their visual impairments, how they learn best, and what they needed to be successful in the classroom. The students verbalized what they would write, and I guided their formulations by asking questions. Those steps helped them to communicate more effectively. Excerpts from their letters speak for themselves.

Student One.

“When I was little, I had a tumor in my left eye, so the doctors had to remove it and replace it with a fake eye, called a prosthesis. On my right eye, I had a cataract and the doctors also removed that. I have low vision in my right eye. I can see everything, but I cannot read small print or see things far away like the chalkboard.

I am good at working on the computer and I am good at typing.... I am very good at socializing with people. Science is one of my weaknesses. Another one of my weaknesses is working too fast and not checking my work. I am very weak at editing my work. Sometimes I need help.”

Student Two.

“I only have central vision and cannot see on the sides. It is difficult for me to locate things and impossible to read print. I can see the letter but too many things on a page are confusing. I use Braille ‘n Speak, which is a Braille notetaker. I also have some spatial problems like finding where I am and copying things. I sometimes have trouble locating things visually, but once I find what I’m looking for, I can see it clearly.

“I love to write, but spelling and comprehension are not my strong suits. I take tests orally and use a Braille copy when there is time. It is easier for me to concentrate when there are no distractions.... Before I take a test I like to get study guides in advance so I can be prepared. It helps me to know a week in advance.”

Student Three.

“I had some vision until the age of nine.... I’ve had several different surgeries to attempt to bring back my vision, but all of them were unsuccessful. Having a Braille copy gives me that very same independence (as the sighted kids). However, my independence is limited in some respects, such as when the class watches a video, when there is a mostly visual project, or simply when the teacher draws diagrams on the board. Having a person available with good description skills is very helpful.”

Student Four.

“I can see most objects clearly, but not the details, and I can also see colors. However, I cannot see things that are tiny, far away, or faintly printed. My field of vision is impaired, so sometimes I have to turn my head to see things. If you cover one eye and slightly close the other, you may be able to get a feeling for what I can see. Sometimes I get stressed out, so it helps when I know long term assignments, including novels, and tests ahead of time.”

FOLLOW-UP ACTIVITIES

After the letter-writing activity, we talked about ways to keep written records of “what works for me” in different classroom settings and ways to optimize learning styles with a variety of teaching styles. Talking to high school students with visual impairments, being around people with a positive, “can-do” attitude, and role-playing helped to give the eighth graders practice using a variety of strategies. Growing from mistakes, solving problems collaboratively, and learning to give and accept praise and criticism occurred as a result of this project.

This student-centered project, which could be used in a variety of school settings and with a wide range of disabilities, will continue throughout high school and will provide important documentation of student growth. Revision will occur at least annually, or on an as-needed basis; the students will select the contents for each section. The self-advocacy portfolio serves as the basis for the IEP transition plan, which focuses on career information including interests; strengths and capabilities; challenging, yet attainable vocational goals; and activity-based goals. Adding photos or videos; notes on observations of mentors in areas of interest; ideas about internships; comments by teachers, parents, rehabilitation workers, and employers; and selected journal entries related to vocational goals would strengthen the portfolio.

SUMMARY

Students with visual impairments need to know how to assess themselves, set educational and vocational goals, understand what accommodations work best for them, learn how to use resources and make requests, and determine how to solve the inevitable problems that will arise in high school. Ongoing instruction in self-advocacy skills helps students prepare for success as independent adults in the work world, as evidenced by these evaluative comments made by the four students at the end of the first year of the project.

Student One. “Different things work with different teachers. I am not afraid to ask for the things I need to learn.”

Student Two. “When people look at me they sometimes don’t believe that I am blind and have many challenges. My teachers have tried to describe my vision to others, but I think it is better if I explain my own disability.”

Student Three. “Job exploration is very important, but self-motivation is the key.”

Student Four. “I get this very good feeling when I feel like I’m independent. In real life you have to step out for yourself and say, ‘This is what I need help with.’”

REFERENCE

Brinckerhoff, L. C. (1994). Developing effective self-advocacy skills in college-bound students with learning disabilities. *Intervention in School and Clinic*, 29, 229-237.

New Teacher Series: Getting Started with Activity Routines Ann Rash and Nancy Toelle, TSBVI Outreach

The most important tool in the TVI’s toolbox when working with MIVI students is collaborative consultation regarding activity routines. A well-written routine will incorporate aspects relating to all disciplines working with the child: occupational therapist, physical therapist, speech therapist, teacher of the visually impaired, teacher of the auditorially impaired, classroom teacher, parent. Remember the overriding purpose of activity routines is to provide the child with a pleasurable experience that they will want to participate in, will anticipate, and communicate about. Also keep in mind that the very first step to implementing routines is to build a relationship with the classroom teacher and assistants so that they will be open to trying this approach.

Though we feel strongly that activity routines are appropriate for all MIVI students, we recommend that for your first trial you select a student who: attends school regularly, has a teacher who is willing to try new techniques, has demonstrable likes and dislikes and has periods of alertness during the school day.

STEPS FOR INCORPORATING ACTIVITY ROUTINES INTO YOUR PRACTICE:

1. Informal assessment of the student:

- *Appetite and aversion inventory.* Make a list of the student’s likes and dislikes. For example: water play, singing, being held closely, vigorous movement, cuddling, food. This information should come from those most familiar with the child, including parents. The key to this step is to use the activities liked by the child and avoid the dislikes.
- *Biobehavioral states.* When is the child awake and alert for learning? Ask classroom staff and parents to make note of the child’s most alert times of day. Learning cannot occur if the child is distressed, hungry, or asleep.
- *Orienting reflexes.* Determine what calms and/or alerts the child to be ready to learn.

2. Writing the routine:

- Develop a trial routine based on the child's likes as found in the informal assessment information.
- The TVI, classroom teacher, and other related staff available draft a script of the steps for a sample routine, including: positioning, spoken language/sign to be used, location and materials.
- The group agrees on an activity that is highly pleasurable, simple to do, brief, and fits easily into the classroom schedule, and is well within the child's current range of abilities. Once an initial routine is learned, steps can be incorporated to increase the level of challenge.
- A routine is developed with a note taker being responsible to produce copies for all (frequently the TVI).
- Once a copy is in hand, circulate it to any member of the team who was absent to make sure issues relating to their discipline are addressed properly (positioning, language, etc).
- Set a date to give the routine a try and see how all the steps work and make revisions, as needed.
- Produce a final, revised routine.

3. Implementing the routine:

- The routine will need to be done at least once daily (or as frequently as the child is in school) at the time that it fits in the schedule; can be done exactly as scripted, always in the same location, and with the same materials. Remember, the goal is to build memory and anticipation!
- The final routine should be demonstrated and practiced with whomever will implement it.
- Pick a date to begin that is not before a holiday or when student will be absent for a prolonged period.
- Start the routine and pay attention to the child's responses to each step: both of you should be enjoying it. Look for: anticipation, participation, pleasurable response, and effort to communicate a desire to continue.
- Keep in mind that you will be establishing a baseline for this child's ability to learn a new routine and that we simply don't know how long that will take. Be prepared to stick with it; don't give up.

Once this routine is firmly established, develop another pleasurable routine, following all the guidelines presented above. This sets the stage for choice making and incorporating these activities into a calendar or schedule of meaningful activities for the child. Eventually, you will be able to sandwich a not-so-pleasurable routine (tooth brushing, face washing) in between highly pleasurable ones.

SAMPLE ACTIVITY ROUTINE:

Rocking with a young child (consult with speech therapist regarding the signs for "more" and "finished"):

1. Start by going up to the child with pillow, blanket or other object prompt and say, "Let's rock!" and help them make a rocking movement with their hands/arms.
2. Take the child to the rocker (plain chair or place on the floor where you can rock slightly if no rocker is available).

3. Say, “Let’s sit in the rocker (chair/floor),” and seat yourself and the child with the pillow or blanket touching the child.
4. Start rocking and sing a rocking song, such as “Rock, Rock, Rocking with Amy”. Sing the line three times before saying, “STOP!”
5. Stop and wait for 15 seconds to see if the child indicates in any way that he/she wants to continue.
6. Ask “Do you want more?” You may help the child make the sign for more.
7. Repeat the rocking, singing, and the STOP several times, as long as the child is enjoying it and is engaged.
8. Look for anticipation, participation, communication, and enjoyment on the part of the child.
9. When ready to end, say “We’re finished (or all done),” help the child make the finished sign, and get up from the chair immediately.

SUGGESTIONS FOR OTHER SIMPLE ROUTINES:

- Cuddling – object prompt could be a blanket or stuffed animal
- Water play – object prompt a water toy or bottle of liquid detergent to make bubbles
- Hand lotion – object prompt a pump lotion bottle
- Brushing – object prompt a soft therapy brush (check with OT before implementing)
- Bouncing – object prompt therapy ball
- Music – object prompt switch to turn music on
- Play with vibrating toy – object prompt is toy

SAMPLE IEP OBJECTIVES TO SUPPORT THE USE OF ACTIVITY ROUTINES:

These objectives could be implemented by the OT, PT, SP, AI, O&M, TVI, and classroom staff

- Will demonstrate anticipation in the use of 10 familiar objects used in daily routines by appropriate associated actions.
- Will demonstrate anticipation of the next step in specified daily activity routines.
- Will actively participate in specified daily activity routines by movement, communication, use of vision and hearing. (Massage, brushing, switch use, diapering, position change, feeding, and play.)

RESOURCES FOR MORE DETAILED INFORMATION:

Communication: A Guide for Teaching Students with Visual and Multiple Impairments, by Linda Hagood.

Teaching Students with Visual and Multiple Impairments: A Resource Guide, by Millie Smith.

Calendars for Students with Multiple Impairments Including Deafblindness, by Robbie Blaha.

Search the TSBVI Web site for more articles from *See/Hear*.

Strategies for Using Voice Output Communication Devices With Children who are Deaf-Blind

By Maurice Belote, Project Coordinator, California Deaf-Blind Services

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WHAT IS A VOICE OUTPUT DEVICE?

A voice output device is an electronic device that “speaks” for a child. When activated by the push of a button or using an adapted system, the child can expressively communicate one or more messages. The messages are recorded specifically for that child, so that they are relevant to the child’s needs and environment. These devices are typically commercially produced by manufacturers in the field of augmentative communication systems. Voice output devices have been used successfully by many individuals with combined vision and hearing problems, and there are instances where the use of a voice output device has provided a child or young adult with their first true success at expressive communication using a formal system. The device becomes an important component of the child’s expressive communication system, along with other possible expressive modes such as speech, objects, signed communication, pictures, gestures, etc. The touch pads on these devices can have printed words, line drawings, photographs, textures, objects, or any combination of these to represent the contents of each recording.

WHAT ARE SOME STRATEGIES TO CONSIDER WHEN USING VOICE OUTPUT DEVICES?

The following are some strategies that may be helpful when using voice output devices. Throughout these strategies, the term “user” will be used to refer to the individual who uses the voice output device.

1. Give careful consideration when choosing the person who records the messages. When possible, choose someone of the same sex and near the same age of the user. For users who are hard of hearing and young, however, don’t choose a child who is so young and has a voice so soft that it will be difficult for the user to hear it.
2. Make certain that the person who records the voice isn’t someone known to the child. It can only truly be the user’s voice if the recorded voice is a neutral party. It isn’t likely that most users want parents, siblings, or teachers to be their voice, except in occasional situations when no one else is available and a message is needed on the spot.
3. Pay close attention to any slang or vernacular used in the age group of the child, the use of which will give warmth and personality to the child’s communication.
4. It is extremely important that the device never “speaks” if the user isn’t the one who has pushed a button to make it speak. It is very confusing to a user to hear his or her voice output device say something that he or she didn’t intend. For example, imagine a child sitting in his classroom and then hearing his voice output device from across the room say “I’m thirsty; I want some juice please.” The child’s reaction may be to think, “Wait, I never said I want juice—I’m happily involved in an activity right now!” If a service provider or family member needs to test the device, check its power, etc., the device should briefly be taken somewhere where the user won’t hear the voice activated by others.
5. The user must have access to the device at all times. Opportunities for communication occur throughout the entire day. For some users, having a voice output device might provide them with their first real success at formal expressive communication and, while temporarily relishing the newfound power and control over their environment, they may activate a message over and over. In these instances, we might be tempted to put the voice output device on a shelf out a reach of the user, but we can’t do this. Taking a user’s voice output device away because it is annoying to us would be like taping a verbal

child's mouth closed because the child says the same thing over and over throughout the day. Instead, think of these situations as great teachable moments to reinforce the use of schedule/calendar systems, and explain to the user that while it may not be the appropriate time to do whatever it is the user wants, there may be an opportunity later in the user's schedule.

6. Children are naturally curious, and the classmates and/or siblings of the child with the device will probably want to touch, play with, and explore the device when it is first introduced to the classroom and/or home. In fact, there are some children who simply will not think about anything else until they have had a chance to touch the device. To satisfy their curiosity, give these children an opportunity to play with the device, perhaps during a morning circle activity or for a half-day in small groups. Make sure that the user is either a direct part of this or out of hearing and vision range to know its happening. After this activity, the other children can be told that they have had their opportunity, and they are never again allowed to push a button to make the device speak. Of course, if they're assisting the user to use the device effectively, that is another matter—we want to encourage natural peer supports whenever possible.
7. It will be necessary to teach the user how to use the device, but this instruction must be conducted in the context of naturally occurring, meaningful activities. It will be confusing to the user if he or she is expected to participate in drill activities in which the device is used purely for instruction.
8. When choosing the phrases/messages that will be included on the device, try to consider meeting everyone's needs, including the users. For instance, if a device only has nine possible phrases, it may be tempting to fill all nine with phrases that make life easier for caregivers and service providers, such as "I need to use the restroom". If the user has a particular interest, e.g., a favorite pet, a hobby, a collection, family members, a favorite place or activity, consider including a message or messages about these interests. Similarly, think about the user's age, and what other children at that same age are interested in. Be sure to include some of these interests on the device as well. This will give the user something to use as an icebreaker or conversation starter with peers.
9. For users who do not have enough residual hearing to hear what the device says, the team may want to adapt the device with a signal (light or vibrator) that lets the user know the device has "spoken" effectively. For example, it would be frustrating and counter-productive for a user to think their device has "spoken" when in fact the device's battery is dead. In this case, the user would be waiting for a response from their communication partner, and be confused by this lack of response.

Update: Educational Interveners in Texas

by Robbie Blaha, Texas Deafblind Project

Children with deafblindness in early intervention and school settings have unique educational needs due to the combined effects of their dual sensory loss. As result, the families and educators who comprise the IEP teams must have information about deafblindness to develop and implement an appropriate IFSP or IEP. Paraprofessionals can play an important role in this process.

Services are more effective when paraprofessionals have training and skills in the area of deafblindness and clearly understand their role on the child's educational team. The Texas Deafblind Project continues its efforts in supporting and expanding effective paraprofessional services. A critical part of this effort is the focus on the Intervener Model. An intervener is a paraprofessional with specialized skills and training who is designated to provide direct support to a student with deafblindness for all or part of the instructional day, supporting the rest of the team in implementing the student's IEP.

WHAT'S HAPPENING WITH THE PARAPROFESSIONALS SERVING THE STUDENTS WITH DEAFBLINDNESS IN TEXAS?

The Texas Deafblind Project is funded by the U.S. Department of Education to support and train people involved with students who are deafblind. Project activities include developing training products for and about interveners, tracking interveners in Texas, providing training for interveners, and participation in national activities regarding the use of interveners. The following is a snapshot of what is happening this year.

HOW DO YOU IDENTIFY THE TRAINING NEEDS OF INTERVENERS?

One product developed by the Project is a list of competencies, or skills and knowledge, every intervener should have to work effectively. This allows interveners and those on their teams to evaluate what training is needed to help the intervener support students who are deafblind better. This document is tailor-made for interveners in Texas, and is based on information developed and used around the country.

Each intervener identified in Texas is asked to fill out the competency form, keep a copy, send one copy to a local administrator, and mail another copy to the Texas Deafblind Project. The Project looks at the needs revealed in the competency forms when designing statewide training activities. The Project is also beginning to explore the possibility of training interveners for college credit in Texas.

This year the Deafblind Specialist at each Education Service Center (ESC) will be mailed a summary of the needs indicated by the Intervenors in his/her region. This can help guide the training at the regional level. So not only do these competencies give districts a way to track progress of their staff, but they help guide technical assistance efforts around the state. The competencies for each intervener are updated annually. New competency forms have been mailed this fall to participating districts. If your school district is using an intervener and interested in participating, contact the Texas Deafblind Project for more details.

WHAT TYPE OF TRAINING RELATED TO DEAFBLINDNESS IS AVAILABLE TO THE INTERVENERS AND OTHER PARAPROFESSIONALS SERVING THIS POPULATION?

The biannual Texas Symposium on Deafblindness offers a variety of topics that have been requested by interveners and their teammates. Eighteen interveners/paraprofessionals attended the 2001 Symposium, and we hope to see even more in 2003. An award for the Outstanding Intervener will be presented during the closing general session. Also, this year there will be a working luncheon for interveners during the symposium to support networking and information sharing. On years opposite the Symposium, there is a statewide intervener conference in the fall. To participate in this, the intervener must have a current set of competencies on file with the Project, and attend with a professional from the educational team.

Workshops on deafblindness are offered at many of the Education Service Centers as well. Contact the Deafblind specialist in your region for dates and topics. You may also check TSBVI web site for a list of trainings in other regions. Another option for training is onsite technical assistance regarding a particular student. Information on this type of training may be obtained from your ESC Deafblind Specialist or the Texas Deafblind Project.

By the way, interveners don't just attend training; sometimes they provide it to others. Three of the current interveners have presented with their teams at statewide trainings over the past several years.

WHERE ARE INTERVENERS BEING USED IN TEXAS?

The Texas Deafblind Project database lists interveners in 14 of the 20 regions of Texas. Intervenors are identified in a variety of ways. The Texas Deafblind Census form asks if an intervener is assigned to each child

reported. Interveners are also identified by a call from a district or an ESC deafblind specialist. The Project has a database tracking intervener location and training.

CONCLUSION

The Intervener Model is gaining recognition and being used more frequently throughout the state and country. A national position paper on interveners was developed, reviewed, and made available from NTAC <www.tr.wou.edu/ntac>. Materials on interveners in Texas are available from the Texas Deafblind Project <www.tsbvi.edu>. For more information, or to take part in intervener training opportunities, contact the Texas Deafblind Project at (512)206-9242.

Out of the Corner and into the Class:

The Role of the Intervener with Deafblind Children

By Beth Fox

Reprinted with permission from *VIBRATIONS* newsletter of Colorado Services for Children Who Are Deafblind, Fall 2001 Edition: Focus on Interveners

VIBRATIONS Editors Note: Beth attended the 2001 Summer Institute on Deafblindness and this is the paper she turned in for university credit. Beth captured many key points that were made by Linda Alsop during the two-day training. Thank you, Beth, for putting your notes in such an easy to read format about the role of interveners.

WHO IS THAT CHILD SITTING ALONE IN THE CORNER OF THE ROOM?

It may be a child who is deafblind. Deafblindness is a complex disability, which is characterized by a combined loss of vision and hearing. The vision and hearing loss is compounded exponentially when there are additional disabilities to create extreme challenges in the areas of communication, development of interpersonal relationships, behavior, sensory integration, and motor and cognitive development.

WHY DOES THIS CHILD NEED EXTRA HELP BEYOND CONVENTIONAL SPECIAL EDUCATION?

Due to the child's dual sensory loss, she lacks access to information. This challenge may prevent the child from interacting with her environment and encourages isolation and internalization with focus upon self-stimulation. The less a child interacts within her environment, the fewer chances she has to learn.

WHAT WILL IT TAKE TO HELP MOVE THE CHILD FORWARD AND CLOSER TO HIS OR HER CLASSMATES?

A person who can consistently bridge the gap of sensory deprivation so that the child can receive information and become linked to the world around her is needed. This person is called intervener. The intervener can provide information to child so that she may better understand her environment and act appropriately within it. The intervener serves to interpret information from the child and also acts as a conduit for communication between the child and others. An intervener could be described as a consistent filter, communication cable, facilitator, or bridge.

An intervener does not control, create dependency, make decisions for the child, or stand as a barrier between the child and others.

IS THE INTERVENER PRESENTED WITH MANY CHALLENGES IN ASSISTING THE CHILD ALONG THE PATH TOWARD HIS CLASSMATES?

The intervener must learn all about the child who is deafblind and appreciate her uniqueness. This person should have a secure understanding of the child's vision and hearing and how information is received. Much time will be spent learning about the child's personal system for information exchange. These things will be the basis for building a communication system that will eventually link the child to her environment and the people who are active within it.

WHY IS THIS INTERFACE BETWEEN THE CHILD AND INTERVENER SO IMPORTANT?

A monitor and keyboard are cabled to a CPU of a computer so that information can be entered and returned. These pieces are not unlike the relationship between an intervener and the child with combined vision and hearing loss. The child, like the CPU, is a full of power but can only make an impact with the proper access pieces, otherwise, it will be left in the corner and the potential to positively impact the environment will be left undiscovered.

HOW WILL THE INTERVENER GUIDE THE DEAFBLIND CHILD TO THE MIDDLE OF THE ROOM?

The child will gravitate toward her peers through learning. Curiosity equals learning and the intervener can fuel the child's motivation for curiosity. The intervener will help the child understand concepts and facilitate this transfer from the home environment so that concepts may be generalized to a variety of situations. The intervener ensures that the child has access to the results her trial and error learning so that education can occur. The constancy of the intervener will discourage stress in the child and allow her to learn more easily.

CAN THIS CHILD EXHIBIT BEHAVIOR THAT IS SUITABLE FOR A CLASSROOM SETTING?

An intervener can chart behavior so that it can be understood as a means of communicating why the child is frustrated, hurt, etc. "Inappropriate" behavior is generally due to lack of information. Once the behavior is understood and communication systems are established then the proper information can be conveyed to the child.

HOW WILL AN INTERVENER SIGNIFICANTLY IMPROVE THE LIFE OF A DEAFBLIND CHILD WITH REGARD TO THEIR PEERS AND CLASSROOM EXPERIENCES?

An intervener can include a child with combined vision and hearing loss in class activities and limit problems of isolation by providing information to child and allowing her to interact with classmates. The intervener plays an important role in facilitating introductions of new people to the deafblind child and, over time, can release child to the new person. An overwhelming portion of learning is tertiary (comes from simple observation) and this incidental learning does not occur in individuals with sensory deprivation unless an intervener is constantly present to inform the child about who or what is around her and what is occurring with these people, situations, or objects.

IS THE INTERVENER A CLASSROOM TEACHER?

The intervener is not the classroom teacher but provides no less a vital service than his or her counterpart. The intervener is under the direction of the teacher and the relationship between the two must be emotionally strong. It may take much effort for each person to be able to discuss, explore, and work together to create the best possible learning situation for the child. The teacher and intervener must respect each other and all people who work in various roles with the deafblind child. When this practice occurs teachers, interveners, and all students will meet at the center of the room and will benefit greatly.

Sexual Health Care – Excerpts from *Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed*

Reprinted in part with permission from DB-Link

By Kate Moss, Education Specialist, Texas Deafblind Outreach

Editor's Note: In September of 2001, DB-Link published a book, Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed, that was written by Robbie Blaha and Kate Moss from the Texas Deafblind Outreach Project. What follows is an excerpt of Chapter 8, Sexual Health Care from this book. The entire book is available free from DB-Link in a PDF file version that can be downloaded from their website at <<http://www.tr.wou.edu/dblink/pdf/sex-ed.pdf>>. If you do not have internet access, you can request a copy in print from DB-Link by calling, writing, or emailing to:

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ISSUES FOR THE CHILD OR YOUTH WITH DEAFBLINDNESS

- Certain etiologies may have implications for sexual health.
- A child with deafblindness and significant developmental delays may not be able to successfully communicate problems about his or her health.
- These individuals may be uncooperative about participating in medical procedures and exams.
- Sexual contacts with others may lead to pregnancy or sexual transmitted disease.

ISSUES FOR PARENTS AND PROFESSIONALS

- Parents and professionals may be focused on more demanding medical needs.
- Like the rest of society, parents and professionals may view the child or young adult as asexual.
- Families may look to professionals for help in addressing sexual health issues. (Editor's note: Often these professionals, even medical professionals, may not know what to suggest for the child who is deafblind with developmental delays.)
- Education and rehabilitation professionals may feel unprepared to address these issues.
- Both families and educational or rehabilitation professionals may be unaware of the laws related to medical consent, birth control, surgical sterilization, or pregnancy.

GUIDELINES FOR INSTRUCTION AND INTERVENTION

Acknowledge your child's sexual health needs

The first step towards acknowledging your child's sexual health needs is to remember that your child is sexual rather than asexual. Until you can begin to see your deafblind child as a person who is a sexual being, you can easily overlook his or her needs in this area. Remember that this is the aspect of physical development in which your child is most likely to resemble typical peers.

Advocate within the medical community to ensure the provision of appropriate services

As a parent or caregiver, you will need to become familiar with the types of medical exams that are appropriate for an individual your child's age. Search for a doctor who is willing to collaborate with you in planning for these examinations and who will give you and your child the extra time and attention that may be needed. Talking with other parents of children with special needs may help you to locate the kind of physician you want.

Just as you plan for vaccinations, regular dental exams, and other routine wellness activities, include planning for exams that address your child's sexual health. Your doctor or nurse can provide some timelines for when these exams are typically done. They should include pelvic and breast exams beginning in your daughter's late teens. As she ages (about age forty) mammograms are recommended. Your son should have regular testicular exams. As he ages (about age fifty) you may want to include prostate exams as well. Discuss with your doctors what is involved in these exams, the age that is recommended for beginning them for a person without disabilities, and how frequently they should be repeated. They should be included as part of regular physicals for the individual with deafblindness and significant developmental delays.

Understand how the etiology affects sexual development and sexual health

There are specific syndromes that may result in deafblindness, and many of these have aspects that affect sexual development and sexual health. Some syndromes may typically have early onset of puberty; others may result in delayed puberty or puberty that is absent without hormone therapy. Some syndromes have behavioral characteristics that result in excessive anxiety or pain. These behavioral traits may escalate with the onset of puberty, the pain of menses, and so forth. Get as much information as possible about the impact of your child's etiology on his or her sexual development and sexual health. Make sure your doctor and other caregivers are aware of these issues too. Good resources for finding this type of information are national support groups or foundations that focus on particular syndromes or conditions or NORD (National Organization for Rare Disorders).

Share a complete family medical history with your doctor

The child with deafblindness and developmental disabilities does not escape increased risks for medical conditions that may be hereditary. For example, if there is a high incidence of ovarian cancer in your family's history, your physician should know that information. It may not mean that your deafblind daughter will have ovarian cancer at some time, but just like your other daughters, she may need to be watched more closely for the condition. Also, a thorough family medical history may be helpful in determining safer birth control medications and may have impact on other types of medical treatment.

Know the laws that relate to managing your child's sexual health

Children in this group may never be able to manage their own health or make independent decisions about birth control, reproduction, pregnancy, medical intervention, and so forth. However, parents should not assume that they always call the shots for their child. There are certain health-related issues that can be addressed by a parent only until the child turns eighteen. At that point, some type of guardianship may give parents partial control over medical interventions. It is important to know your state's laws about medical decisions that are specific to sexual health. For example, there are abortion laws specific to every state. If your daughter were to become pregnant, you may or may not be able to make a decision for her about an abortion. Additionally, surgical sterilization may not be permitted just because you request it. Although many parents feel that this is the appropriate way to ensure the deafblind child's health, there are some important legal considerations of which parents should be aware related to this issue. The American Academy of Pediatrics' Committee on

Bioethics advises that physicians be aware of state law dealing with the age of consent and the sterilization of minors with developmental disabilities. They write:

The age of consent, including that for surgical procedures, varies from state to state. Some minors may be old enough under applicable laws to be considered eligible to agree to sterilization if otherwise capable of doing so. In such cases, a careful clinical assessment of decision-making capacity must be performed by a professional skilled in and experienced with evaluating the capabilities of persons with disabilities, such as a psychiatrist, licensed psychologist, social worker, or pediatrician. Adolescents who have been declared by judges to be mentally competent for the purpose of accepting or refusing sterilization are entitled to make whatever decision they believe furthers their own interests. In some states, laws or court precedent forbid procedures aimed primarily at accomplishing sterilization solely on the authorization of parents or other legal guardians consulting with appropriate physicians and surgeons. When the involved parties believe surgical sterilization to be the best option, application to the courts may provide the only lawful means to accomplish that goal. Physicians and surgeons should be familiar with the law that applies to the jurisdictions where they practice.

Committee on Bioethics, American Academy of Pediatrics - Sterilization of Minors With Developmental Disabilities, Pediatrics, August, 1999, 104(2) p337-341.

The laws related to sexual health, consent, and personal liability can be overwhelming to both parents and caregivers. It is understandable that they may sometimes feel it is easier to avoid the issue altogether. After all, maybe nothing will happen. It is important to remember that failure to address a child or young adult's health needs may be considered neglect. Parents and other caregivers must understand their responsibilities and limitations under the various federal, state, and local laws.

Typically your doctor should be able to help you get this information. Other resources include lawyers who are experienced in guardianship issues; national, state and local Association for Persons with Mental Retardation (ARC), your state's child protection and advocacy agency, and your state's parent training and information center. For your protection, as well as for the protection of your deafblind child, learn what your state laws are related to managing your child's sexual health. If you are a professional working with an adult residential program, your program should have very clear policy relating to the management of clients' sexual health-care needs. This includes defining how decisions about medical treatment, birth control, consensual sex, and pregnancy will be handled, the rights of the parents/guardian, and the rights of the individual with deafblindness and additional developmental disabilities.

Tap into the expertise of seasoned professionals and parents with older children

Parents can feel very alone when trying to manage their child's sexual health. It is always helpful to talk to another parent who has already dealt with these issues. He or she may not have the answer that is right for you and your child but may be able to help you clarify your concerns and point you in the direction of resources. Parent support organizations such as National Family Association for Deaf-Blind (NFADB) or ARC, state-level support groups, and local groups are a good place to go to make these connections.

There are also educational and medical professionals who are knowledgeable about issues and resources. Bring your concerns to your child's educational or rehabilitation team. Talk to your family doctor, Planned Parenthood, or school nurse. The more you know, the easier the decisions will become and the better your choices will be. Silence and worry will not get you or your child with deafblindness very far. Educational and rehabilitation professionals should also make use of these resources. The more information they have, the better prepared they will be to help the family and the young adult with these issues.

Include IEP goals that help prepare for medical examinations

Like any other area of sexuality, managing sexual health issues is a skill that an individual with disabilities needs to live a happy and healthy adult life. It is appropriate to focus on skill development related to these needs as a part of the child's educational program. The goals of instruction should be very limited. Typically he or she will not be making decisions about birth control, medical procedures, and so forth. Instead the goal for instruction should be to reduce anxiety and to gain better cooperation during examination and treatment.

Develop concepts

There are specific concepts that the child with deafblindness and significant developmental delays will need even if he or she is not capable of participating in sexual health-care activities. For example, not understanding what is happening during a medical examination of any kind can be traumatic for the child. Learning concepts such as "penis," "vagina," "breast," "doctor," "nurse," "examination table," "calm," "wait," "touch," "lie down," "temperature," "blood pressure," and so forth are important. If the child understands these concepts it will be easier to explain what will happen during an examination.

Release staff to support the child during the examination

At the family's request, schools should consider allowing release time for staff to support families during these exams. This experience is one that can be used by educators and parents to work on many important life skills for their child or young adult and it will involve some planning. For some school programs, it may also require persuading higher-level school administrators to support the effort. But the benefits to the medical staff, the family, and most importantly to the child are worth it. Since participation in medical examinations and procedures is probably certain to be a regular part of deafblind individuals' lives, this level of instructional support leads to important adult outcomes.

Take a distraction to the exam

Bring along a favorite toy or object to distract the child when he or she becomes anxious during a doctor visit. For example, one young woman was very fond of plastic flowers. When she arrived at the doctor's office, her parent gave her a new bunch of flowers to hold in her hands. They talked to her to keep her attention engaged on the flowers rather than on the doctor's activities.

When the exam is finished, help the child deal with his or her feelings

These examinations have a big impact on some children and young adults. It is important to take time after the visit to talk about what happened. Collect items from the visit that can be used in a story bag or box to review what happened, then placed in a finished box on a calendar. This often helps the child know that the exam will not happen again today, and allows everyone to get back to a normal routine. For children who are able to use more sophisticated calendar systems, looking forward in time to discuss that there are no more examinations scheduled in the near future can be helpful as well. Set aside opportunities to review and share the experience, affirming what has happened, how well the child did, and that the exam is finished.

Use Routines

Developing a routine around a visit to the doctor can reduce anxiety for the child. This type of routine is good for any kind of visit, not just ones related to sexual health. Before you take the child in for a particular examination, find out what will happen during this visit, and incorporate the details into a step-by-step routine.

Practice the routine by going through some of the steps with the child. For example, practice changing into an examination gown, having his or her blood pressure checked, and getting on and off an examination table.

The school nurse could assist with the practice of these activities. If you don't have a school nurse, talk to your family doctor about setting up some practice visits to the office. Ask the school to allow educational staff to plan an individual "field trip" to the doctor's office. The teacher can then support the child and you in becoming familiar with the examination room and the devices that may be experienced during the visit.

Use calendar systems

If the child uses any type of calendar system, represent the activity with some type of symbol. This can help the child anticipate when visits might occur and when they are finished. Also if he or she can anticipate a favorite activity after successfully completing the examination, getting through the event will be easier. For example, when you sense anxiety building during any part of the exam, you can reassure the child by reminding him or her, "Wait, calm, lie down. Finish, then ice cream." Bring along the symbol for ice cream and show it to him or her. Don't hesitate to use bribery. This is one time when his or her favorite reward should be a guarantee.

Develop instructional units for certain children

Some children benefit from a unit related to medical exams. For the student who can categorize and who already has the ability to represent information in an abstract manner (pictures, print, signing, etc.) the use of instructional units is important. Since male and female wellness checks (pelvic, breast, testicular, and prostate examinations) are such a different experience from other types of examinations, the deafblind individual can benefit greatly from some advance preparation. You could begin an examination unit even at a young age and limit the focus to temperature, blood pressure checks, and so forth. As the young adult nears the age for a breast, pelvic, testicular, digital rectal examination, these new aspects could be added to the routine.

Sample Unit on Preparing for a Well-Woman or Well-Man Check

Concepts To Learn:

- Names of the body parts involved in the examination (breasts, vagina, testicles, rectum, etc.) and other concepts such as doctor, nurse, examination, table, lay down, gown, lamp, calm, wait, hurt, change, on, off, touch.
- You change into a gown for this type of visit. You will put your clothes back on soon and leave. (For those individuals who associate the gown with being admitted to the hospital, assure them that there is no hospital stay involved in this procedure.)
- Other men/women the student knows have these visits as well. (Mom, Dad, the school nurse, the teacher, Uncle Bob, Aunt Kay).

Activities For Instruction:

- Using an anatomically correct figure, simulate going through the doctor's visit step-by-step and discuss. Have the child assist with each step of the activity, and allow plenty of time for him/her to examine the devices that will be used.

Include the Following Steps for Both Well-Woman and Well-Man Checks:

1. Take off the figure's clothes.
2. Change it into a gown.
3. Put the figure's clothes nearby.

4. Put the figure on the examination table.
5. Complete the basic steps involved in any visit on the figure (taking temperature and blood pressure, listening to the heart).
6. Tell the figure to “lay down” and discuss how the figure must stay still and be calm.

Steps to Add for Well-Woman Check:

7. Let the student know that the doctor will pull down the gown to check each breast. Discuss in terms such as, “Wait, patience, calm, doctor okay touch breast.” Demonstrate on the figure and then let the student practice this step with the figure.
8. Put the figure’s feet in stirrups. Discuss in terms such as, “Feet up. Wait, calm, doctor okay touch.” Let the student examine how the feet are placed.
9. If the doctor is going to use a lamp, have one there to use. Let the student explore the lamp, turn it on, and discuss in terms such as “Doctor, light look, okay.”
10. Using the figure, show the student that the doctor will be examining the pelvic area and discuss with her in terms such as “Wait, doctor touch okay, look vagina, hurt little, calm, patience.” (Depending on the student, you may use a swab to insert in the vagina of the figure and discuss in terms such as “Calm, patience, doctor touch in vagina, hurt little, okay.” If there is a speculum available for the young woman to examine, allow her to do so and explain how it will be used. Use the correct vocabulary according to child’s communication level: vagina, vulva, etc. You may let the student be the “doctor” if she can make that association.
11. Tell the figure and have the child tell the figure, “Finish.”
12. Get the figure up, change its clothes, and say good-bye to the doctor.
13. Talk about where the figure will go to have a special reward for being good at the doctor. Be sure to use the reward that will mean the most to the young woman.

Include the Following Steps for a Well-Man Check:

7. Lay the figure on the table and elevate the right leg. Discuss in terms such as “Leg up, wait.”
8. Feel the scrotum area for the right testicle. Discuss in terms such as “Wait, patience, calm, doctor touch testicle, okay.”
9. Roll the testicle between the thumb and fingers to examine. Discuss in terms of concepts like “Wait, calm, patience, doctor hurt little.” You may let the student be the “doctor” if he can make that association.
10. Lower the figure’s leg and repeat with left leg.
11. Tell the figure and have the child tell the figure, “Finish.”
12. Get the figure up, change clothes, and say good-bye to the doctor.
13. Talk about where the figure will go to have a special reward for being good at the doctor. Be sure to use the reward that will mean the most to the young man.

Other Instructional Activities for Both Male and Female Deafblind students

- Borrow a gown from the doctor. Take the child to the school nurse’s office. Have him or her change into the gown, and place the street clothes on a chair. If possible have him or her get on the examination table or a couch. Ask the nurse to go through some of the routine checks like taking the temperature and blood pressure, listening to the heart, and so forth. Have the student change back into his or her clothes. Go for a special reward.
- If the student has enough vision and picture recognition skills, draw sequence pictures that show the basic steps of an examination and discuss each one. Have the child try to find the correct picture representing each step, and then talk about it. Arrange the cards in the correct order as you discuss what happens next.
- Make a field trip to a doctor’s office so the student can see the office and talk through what is going to happen. Take the sequence pictures or object symbols with you and locate the real items (gown, table, stirrups, swab, speculum, etc.) and discuss what will happen. If possible, meet the doctor and nurse. Go for a special reward.
- Schedule the visit in the student’s calendar so he or she can be prepared for the visit. Note that it is a special day, but just part of it will be different from normal. Reassure the child that things will return to normal after the doctor visit is finished.
- After the student is familiar with the process and has the vocabulary, have a familiar same-sex adult talk with the student about having an examination. Make sure this person is prepared to discuss it and can focus on concepts and vocabulary the student is familiar with through your lessons. This adult can assure the student that he or she has had the exam and it was okay. List other people he or she knows who have had the examination as well. It is also a good idea to let the student know the examination is “private” so it will not become a constant topic with the general public.

CONCLUSION

Regular attention to a child or young adult’s sexual health-care needs is critical. Parents and educators should make it a focus of instruction and intervention for the child with deafblindness and significant developmental delays. Parents, rehabilitation staff, and other caregivers must be aware of the laws related to managing sexual health issues, providing birth control, pursuing surgical sterilization, and addressing pregnancy. They should discuss concerns with the young adult’s doctor and plan for his or her needs now and in the future. In making choices about their child’s sexuality, parents can benefit from discussing their concerns with other parents and with caring professionals from the medical, legal, and educational communities. They should advocate for quality health education programs as well as the child’s right to have good sexual health care.

What Is (Or Isn’t) Happening In Texas With the National Agenda

By Phil Hatlen, Superintendent, Texas School for the Blind and Visually Impaired

A few weeks ago a colleague shared with me how excited some of the TSBVI staff were regarding the presentations at AER in Toronto on the National Agenda. And they were wondering what Texas was doing about implementation of the eight goals of the National Agenda. And I think the answer was “...not a whole lot...” In fact, Texas AER decided some years ago to take on one or two goals at a time. And we did well the first few years—we took on goals 6 (assessment) and 7 (materials on time), and Texas looked good on those two. But, it seems that we have lost our focus and momentum with regard to the National Agenda. There are eight goals, and we in Texas aren’t doing so well on the other six. Or maybe it’s that we don’t know how we’re doing!

This article will begin a series in *See/Hear*. For this issue, I am including a recent one-page flyer developed by the National Agenda for local and regional directors of special education (page 30). If you haven't seen this before, I urge you to duplicate it and get it into the hands of special education administrators that you know. Along with this flyer, the National Agenda has two new publications: "The National Agenda: A Parent's Perspective," and "The National Agenda: A Teacher's Perspective." Both of these, as well as the Administrator's flyer, can be downloaded from the TSBVI website. Just go to <www.tsbvi.edu>, pull up the National Agenda home page, and you'll find all three.

In the next issue of *See/Hear*, I'll have a guest author write about the parent's perspective.

Doing Common Things in an Uncommon Way

By Terry Murphy, Executive Director, Texas Commission for the Blind

It's hard to believe that four years have gone by since I was first asked to contribute to *See/Hear* each quarter. As I am writing this article, we are once again in the beginning stages of the biennial appropriations process. Number crunching and negotiating performance goals with the Governor's Office and Legislative Budget Board are starting to dominate my thoughts and plans because my primary responsibility as executive director is to secure an adequate budget for services to blind Texans.

Because there are already signs that this could be the tightest budget year in over a decade, the stress is already building in state health and human services agencies. That's why it was so great today to get a few e-mails from staff to break into all the administrative matters and bring balance to my thoughts. The first was from a blind children's specialist who shared a picture she'd taken of a young consumer perched on his tricycle that had been specially outfitted for his mobility needs. Dad, little sister, and the specialist were alongside for his inaugural confidence-building excursion down the rural neighborhood sidewalk he could not see clearly. The second was from our staff in Lubbock, reporting on the results of our collaborative camping project with several Education Service Centers and TSBVI Outreach. Twenty-nine youngsters spent five days hiking and camping. When asked what they were most proud of, remarks included: "making new friends," "learning to pitch a tent," "making it all the way on the long hike," "finding the bathroom by myself."

The next e-mail was from an instructor at CCRC. She was relaying her experiences with six center consumers ranging in ages from 19 to 40 who had gone "rock climbing" the evening before in a local gym. Two of the six were totally blind; four had a little vision. Challenged by the two to see who could get to the top first, the other four donned blindfolds and climbed to the top of at least one 15-foot wall, exhibiting their willingness and growing confidence to tackle new skills. They had a lot of fun testing their strength, balance, trust, and endurance.

That information alone was enough to make me wish I'd been there climbing with them, away from budgets and meetings, but what followed in her e-mail inspired me even more to fight for adequate funds to continue at full tilt our confidence building activities I wrote about in my first *See/Hear* article four years ago. When the six consumers arrived at the gym, there were many other people there. As the six began their team climbing, some teenagers in the community began to ask them questions. They asked about their blindness, about the blindfolds some of them had with them, and about Criss Cole. Each of our six consumers cheerfully answered their questions and then challenged the kids in this particular group to try climbing with a blindfold to "see what it's like." The kids and young adults around spent the evening exploring the rock wall wearing blindfolds and talking with our consumers. The guy leading the training and working the desk even tried it.

Legislators have a tough job ahead of them this coming session. I wish all of them could have experienced the face on that youngster trying out his wheels for the first time, the excitement of those young blind and visually impaired campers assembling tents, and the pleasure the rock climbers had in sharing their skills at the gym. This is what confidence-building services are about - discovering new ways to accomplish goals without vision and gaining the confidence to encourage others. There's no better substitute than experiencing first-hand the stories these kids and adults have to tell about themselves.

Have a wonderful fall, and remember: "When you do the common things in life in an uncommon way, you will command the attention of the world." - George Washington Carver

Are All Your Students with Visual Impairments Receiving Appropriate Services?

**An Update on the National Agenda for the Education of Children and Youths
With Visual Impairments, Including Those with Multiple Disabilities**

THE FACTS

- Although you may have only a few children with visual impairments in your school district, you are obligated to serve them appropriately under the Individuals with Disabilities Education Act (IDEA).
- IDEA mandates that a continuum of placement options be made available to all students with visual impairments and that districts make students and their families aware of those options.
- Early intervention can improve the educational outcomes for these children.
- Visually impaired students need to learn disability-specific skills such as reading and writing with braille or using low vision devices, travel skills, career education, and independent living skills—from specially trained and certified Teachers of the Visually Impaired and Orientation and Mobility Specialists (COMS).
- Access to instructional materials in appropriate formats is critical to assuring educational progress.

WHAT MUST BE DONE?

- Offer an array of service delivery options for children with visual impairments.
- Support opportunities for partnerships among parents, the medical community, and school personnel that address early detection and services for children with visual impairments.
- Ensure that a person with expertise in visual impairments is available to all students including those in early intervention programs.
- Support the efforts of higher education facilities that train teachers to work in the field of visual impairments and hire their graduates.
- Ensure that teachers who work with children with visual impairments have reasonable caseloads so that special skills can be taught to support educational programming.
- Be aware of community resources, including rehabilitation agencies, consumer and parent organizations, as well as businesses, that can supplement your educational offerings.
- Know the professionals in your area who have expertise in visual impairments—and use them!

- Provide in-service training opportunities for staff who may work with visually impaired children.
- Require efforts to provide timely access to quality materials in braille, large print, and taped formats.
- Ensure that children with visual impairments receive comprehensive assessments under the guidance of personnel trained in visual impairments.
- Require the teaching of disability-specific skills to students with visual impairments.

HOW CAN YOU GET MORE INFORMATION?

- Visit the National Agenda for the Education of Children and Youths with Visual Impairments, Including Those with Multiple Disabilities web site at: <http://www.tsbvi.edu/agenda/index.htm> (includes contact information for your state coordinator and the OSEP Policy Guidance Paper).
- Contact your state’s special school for the blind or visually impaired. If you are unsure of how to reach a special school, call Dr. Phil Hatlen at 512/206-9133; e-mail to: <philhatlen@tsbvi.edu>.

This material was prepared by participants in the National Agenda effort, which is endorsed by the American Foundation for the Blind, the Association for Education and Rehabilitation for the Blind and Visually Impaired, the American Printing House for the Blind, the Council of Schools for the Blind as well as numerous other organizations of and for the blind throughout the United States.

Instructional Materials Accessibility Act Update By Mary Ann Siller, Co-Chair, National Education Program, American Foundation for the Blind

Editor’s Note: It is possible that by the time this newsletter is published, much will have happened with this legislation. To stay current on the Instructional Materials Accessibility Act, you may want to visit American Foundation for the Blind (AFB) at <www.afb.org/textbooks.asp>.

National legislation that defines timely access to print media for children who are blind or print disabled is being debated on Capitol Hill. This legislation is called the Instructional Materials Accessibility Act (IMAA), and the bill numbers for the IMAA are HR 4582 and S2246.

The Senate had planned to move the bill out of the committee on July 31, 2002. However, it was pulled and it has not been added to the schedule, as of yet. The blindness field and the Association of American Publishers (AAP) are continuing to work through the questions and concerns, but time is running out.

HURDLE # 1

Recently, the Office of Special Education and Rehabilitative Services (OSERS) expressed reservations with key areas of the IMAA. Areas of concern included:

- The IMAA requirement that a uniform national electronic file format take precedence over various existing state file format requirements, and
- The designation of a federally funded national repository to store electronic files.

Advocates feel that both provisions should remain in the IMAA.

HURDLE #2

It is also apparent that the state and federal education officials are not fully aware of the problems that blind and visually impaired students regularly confront in getting access to their school books in a timely fashion. Officials need to better understand these problems in order to make a decision on whether to support the IMAA.

If you have an opinion on this legislation and want your voice to be heard, you may wish to:

- Fax a letter explaining your point of view to members of Congress from Texas who are associated with the Committee on Health, Education, Labor and Pensions from the U.S. House of Representatives and have not cosponsored the IMAA (go to <www.afb.org/textbooks.asp> for the fax and phone numbers). The two Representatives are Sam Johnson from Dallas and John Culberson from Houston.
- Fax a letter to your district member in the U.S. House of Representatives and Texas Senators with the same information.
- Contact your state director of education to present your opinion on how this bill will impact children with visual impairments. All key information for fax numbers and e-mails are at <www.afb.org/textbooks.asp>.

AFB keeps track of opinions expressed about relevant legislation. Please send a copy of your letters to Mary Ann Siller at 214-352-3214 (fax) or <siller@afb.net>.

President's Commission on Excellence in Special Education Publishes New Report

By Edgenie Bellah, Family Specialist, Texas Deafblind Outreach

On October 2, 2001, President George W. Bush created the Commission on Excellence in Special Education. The Commission was charged with the responsibility to continue the President's educational vision for America – “an America where every public school reaches out to every single student and encourages every child to learn to his or her full potential.” In order to recommend reforms for the special education system, the Commission heard from hundreds of families, educators, and communities through public hearings and written comments. On July 1, *A New Era: Revitalizing Special Education for Children and their Families* was published based on that input. Following are the Commission's findings as they appear in the report:

FINDING 1:

IDEA is generally providing basic legal safeguards and access for children with disabilities. However, the current system often places process above results, and bureaucratic compliance above student achievement, excellence, and outcomes. The system is driven by complex regulations, excessive paperwork, and ever-increasing administrative demands at all levels—for the child, the parent, the local education agency, and the state education agency. Too often, simply qualifying for special education becomes an end-point—not a gateway to more effective instruction and strong intervention.

FINDING 2:

The current system uses an antiquated model that waits for a child to fail, instead of a model based on prevention and intervention. Too little emphasis is put on prevention, early and accurate identification of

learning and behavior problems, and aggressive intervention using research-based approaches. This means students with disabilities don't get help early when that help can be most effective. Special education should be for those who do not respond to strong and appropriate instruction and methods provided in general education.

FINDING 3:

Children placed in special education are general education children first. Despite this basic fact, educators and policy-makers think about the two systems as separate and tally the cost of special education as a separate program, not as additional services with resultant add-on expense. In such a system, children with disabilities are often treated, not as children who are members of general education and whose special instructional needs can be met with scientifically based approaches, they are considered separately with unique costs—creating incentives for misidentification and academic isolation—preventing the pooling of all available resources to aid learning. General education and special education share responsibilities for children with disabilities. They are not separable at any level—cost, instruction, or even identification.

FINDING 4:

When a child fails to make progress in special education, parents don't have adequate options and little recourse. Parents have their child's best interests in mind, but they often do not feel they are empowered when the system fails them.

FINDING 5:

The culture of compliance has often developed from the pressures of litigation, diverting much energy of the public schools' first mission: educating every child.

FINDING 6:

Many of the current methods of identifying children with disabilities lack validity. As a result, thousands of children are misidentified every year, while many others are not identified early enough or at all.

FINDING 7:

Children with disabilities require highly qualified teachers. Teachers, parents, and education officials desire better preparation, support, and professional development related to the needs of serving these children. Many educators wish they had better preparation before entering the classroom as well as better tools for identifying needs early and accurately.

FINDING 8:

Research on special education needs enhanced rigor and the long-term coordination necessary to support the needs of children, educators and parents. In addition, the current system does not always embrace or implement evidence-based practices once established.

FINDING 9:

The focus on compliance and bureaucratic imperatives in the current system, instead of academic achievement and social outcomes, fails too many children with disabilities. Too few successfully graduate from high school or transition to full employment and postsecondary opportunities, despite provisions in IDEA providing for transition services. Parents want an education system that is results oriented and focused on the child's needs—in school and beyond.

The report sets forth recommendations addressing each of the nine findings. Following is an excerpt from the report, which outlines the Commission’s three major recommendations:

MAJOR RECOMMENDATION 1: FOCUS ON RESULTS—NOT ON PROCESS.

IDEA must return to its educational mission: serving the needs of every child. While the law must retain the legal and procedural safeguards necessary to guarantee a “free appropriate public education” to children with disabilities, IDEA will only fulfill its intended purpose if it raises its expectations for students and becomes results-oriented—not driven by process, litigation, regulation, and confrontation. In short, the system must be judged by the opportunities it gives and the outcomes achieved by each child.

MAJOR RECOMMENDATION 2: EMBRACE A MODEL OF PREVENTION NOT A MODEL OF FAILURE.

The current model guiding special education focuses on waiting for a child to fail, not on early intervention to prevent failure. Reforms must move the system toward early identification and swift intervention, using scientifically based instruction and teaching methods. This will require changes in the nation’s elementary and secondary schools as well as reforms in teacher preparation, recruitment, and support.

MAJOR RECOMMENDATION 3: CONSIDER CHILDREN WITH DISABILITIES AS GENERAL EDUCATION CHILDREN FIRST.

Special education and general education are treated as separate systems, but in fact share responsibility for the child with disabilities. In instruction, the systems must work together to provide effective teaching and ensure that those with additional needs benefit from strong teaching and instructional methods that should be offered to a child through general education. Special education should not be treated as a separate cost system, and evaluations of spending must be based on all of the expenditures for the child, including the funds from general education. Funding arrangements should not create an incentive for special education identification or become an option for isolating children with learning and behavior problems. Each special education need must be met using a school’s comprehensive resources, not by relegating students to a separately funded program. Flexibility in the use of all educational funds, including those provided through IDEA, is essential.

The Commission believes that the same principals of the No Child Left Behind Act should be the driving force behind the reauthorization of IDEA. These principals are results oriented accountability; flexibility; local solutions for local challenges; scientifically based programs and teaching methods; and full information and options for parents. As IDEA is considered for reauthorization, it is anticipated that this report will have a strong influence in moving IDEA towards reform. Parents and professionals involved in the special education system may wish to become more familiar with the President’s Commission on Excellence in Special Education’s report in order to continue having a voice on what is decided. The entire report, which is 89 pages long, may be found at www.ed.gov/inits/commissionsboards/whspecaleducation/reportspcesefinalreport.pdf.

A Parent’s Guide, Serving on Boards and Committees

A Parent’s Guide: Serving on Boards and Committees by Sherri Coles, published by the National Information Center for Children and Youth with Disabilities (NICHCY), looks at common questions about joining a board or committee, and discusses the unique strengths and skills the parent of a child with disabilities brings to the group. This *Parent’s Guide* is accessed through e-mail: <nichy@aed.org> or URL: <www.nichcy.org>. In addition, NICHCY disseminates other materials and can respond to individual requests for information. The information is copyright free. Readers are encouraged to copy and share, but please credit NICHCY.

Websites For Exploring Careers and Developing Work Skills

A great activity for kids and parents to do together is to check out the different types of work people spend their days doing. One great website to explore is *What Do they Do*, an educational site that helps kids learn about what people do at work and how they make our world a better place. After accessing the website at <www.whatdotheydo.com>, just click on the job that interests you. Another great website to check out is <www.mapping-your-future.org>. This site provides information on college planning, career options, and financial strategies. A third website, <www.ed.gov/pubs/parents/LearnPtnrs/index.html>, gives suggestions for helping your child learn to be a responsible person.

American Foundation for the Blind's CareerConnect

CareerConnect is a free, online, interactive employment planning resource, featuring a database of more than 1,000 successfully employed blind and visually impaired persons who volunteer their experience to help other blind and VI individuals navigate a career path. Visit <www.afb.org/careerconnect> to see what all the excitement is about.

AFB's "Livable Communities" Study (AFB Press Release)

The American Foundation for the Blind (AFB) has launched a national research project that will provide information about the "livability" of cities and towns in the United States from the point of view of people who are blind or visually impaired.

AFB's research will identify the criteria that blind or visually impaired people use to assess their communities. AFB is using a "life stages" approach, which will consider what is important for children and youth, working-age adults, and seniors.

The criteria and an initial list of the most highly rated communities will be announced in February 2003 at "Vision Loss in the 21st Century," an international symposium co-sponsored by AFB and the Foundation for the Junior Blind.

The purpose of this project is to help blind or visually impaired people advocate for improving the accessibility of their communities. The project will also provide information resources for blind or visually impaired people—and their families—who are considering a residential move, college attendance decisions, tourist destinations, and the like.

This research goes beyond imagining, toward eventually assuring more livable communities throughout the nation.

For more information, or to participate, visit: <<http://www.afb.org/livability.asp>>
or e-mail <livability@afb.net>
or call (800) 232-5463

All information provided is strictly confidential.

CLASSIFIED

Mail or e-mail your new classifieds to Jim Durkel at:
TSBVI Outreach, 1100 West 45th St., Austin, TX 78756, or JimDurkel@tsbvi.edu.
An up-to-date Statewide Staff Development Calendar is posted on TSBVI's website at <www.tsbvi.edu>.

2003 Texas Symposium on Deafblindness

February 7-8, 2003
Radisson Hotel and Suites, Austin

Please make plans to attend the 2003 Texas Symposium on Deafblindness! The event will bring together families of infants and school-aged children with deafblindness and the professionals and paraprofessionals who serve them. They will have the opportunity to hear a host of experts discuss various aspects of programming for children and young adults with deafblindness.

Limited funding is available to assist participating families with costs related to travel, child care, and registration. The Deaf-Blind Multihandicapped Association of Texas will host a Friday evening social for families, providing them a chance to connect with one another for sharing and support.

Topics will include deafblind-specific information on communication, concept development, behavioral issues, active learning, sexuality education, assessment, etiologies, mental health issues, auditory training, cochlear implants, interveners, technology, vocational programming, innovative training in deafblindness for families and more. Some of our featured speakers include Barbara McLetchie, Harry Anderson, Linda Alsop, Marlin Minkin, Millie Smith, Dr. Fareed Khan, Donald Potenski, Pam Ryan, Rand Wrobel, and Robbie Blaha. Several of our sessions will include a case study format. A special awards luncheon will be held on Saturday to honor outstanding family members, professionals, and paraprofessionals for their contribution to individuals with deafblindness.

Out-of-state participants are welcome. Funds are not available from the Texas Deafblind Project to assist these individuals with conference costs.

Registration flyers will be mailed out this fall to our SEE/HEAR readers.

Information will also be available
on the TSBVI website at

<<http://www.tsbvi.edu/Outreach/deafblind/symposium.htm>>

You may also contact Beth Rees at
512-206-9103 or email her at <bethrees@tsbvi.edu>
to request a registration flyer.

**Developing Communication
Charts for the VI Student
With Multiple Impairments**

December 3, 2002

Region VI ESC, Huntsville, Texas

Contact: Gwynne Reeves at 936-435-2155

Note: This workshop is
from 1:00 PM-3:30 PM

Border Conference:

**Educating Students
With Special Needs**

December 5, 2002

El Paso Marriott Hotel,

El Paso, Texas

Contact: Rick McCarty at 915-780-5091

**Early Intervention/
Programming Strategies
for Infants
with Visual Impairments**

December 10 & 11, 2002

Region XI ESC, Ft. Worth, Texas

Presenter: Dr. Virginia Bishop

Contact: Olga Uriegas at 817-740-3627

Strategies for Tactile Learners

December 10, 2002

Spring Branch ISD Support Center,
Houston, Texas

Presenters: Jim Durkel and Ann Rash,
TSBVI Outreach

Contact: Karen Crone at 713-744-6324 or
<kcrone@esc4.net>

TASH

Our Quest:

Opportunity*Equality*Justice

December 11-14, 2002

Boston, Massachusetts

The 2002 TASH Conference is a showcase of innovative “how-to” strategies, reasearch, and empowering stories. Each of the over 350 breakout sessions include cutting-edge, practical information about changing images, attitudes, and systems to empower individuals with disabiliitiies and their families.

Contact: 410-828-8274

or email <ddotson@tash.org> to receive

a registration packet by mail

or fax or register online at

<<http://www.tash.org/2002conference>>

More Power to You:

**Using IntelliTools for Students
with Visual Impairments**

December 13, 2002

Region IV ESC, Houston, Texas

Presenter: Bruce McClanahan,

Washington State School for the Blind

Contact: Karen Crone at

713-744-6324 or <kcrone@esc4.net>

Speech Therapy Series

**Attending, Listening, and Responding:
CAPD, ADHD, and Similar Disorders**

December 13, 2002

TETN Network broadcast,

Available at all ESCs

Contact: John Bond at (210) 370-5418

**Best Practices
and Classroom Strategies
in Auditory Learning**

January 17, 2003
TETN network broadcast
available at all ESCs
Contact: John Bond at 210-370-5418

**Young Children
with Visual Impairments**

January 21, 2003
Region IV ESC, Houston, Texas
Presenter: Dr. Virginia Bishop
Contact: Karen Crone at
713-744-6324 or
<kcrone@esc4.net>

**Vision Loss
in the 21st Century--
Everybody's Business,
An International Symposium
Addressing the Impact and
Understanding the Challenges
of Vision Loss on Society**

February 19-22, 2003,
Beverly Hills, California
Contact: AFB Communications,
212-502-7615 or <afbnews@afb.net>

TAER

April 24-26, 2003
Omni Hotel, Austin, Texas
Contact: Edgenie Bellah at:
<EdgenieBellah@tsbvi.edu>

Texas Focus 2003:

Focus on Tactile Learning

June 12 & 13, 2003-- Central Texas
Keynote Speaker: Dr. Sally Mangold
Registration information available at:
<www.tsbvi.edu>

**American Association of the
Deaf-Blind--2003 Conference**

July 12-18, 2003
San Diego State University
San Diego, California
Contact: AADB,
814 Thayer Ave., Ste. 302, Silver Spring, MD 20910
310-588-8705 (fax) or 510-797-3213 (TTY)
<tomjill@juno.com>

**6th International
CHARGE Syndrome
Conference**

July 25-27, 2003--Cleveland, Ohio
Contact: Dennis O'Toole,
(2003 Conference Chair):
<conference@chargesyndrom.org>

**13th International
World Conference on
Deafblindness**

August 5-10, 2003
Mississauga, Ontario, Canada
Contact: Stan Munroe at 519-372-2068
Email: <stan.munroe@sympatico.ca>
Online: <http://www.dbconferencecanada.com/>

Technology Distance Ed Presentations for 2002-2003

By Sharon Nichols and Holly Cooper

- 11/20 Accessibility to On-Line and CD Rom Resources for Students Who Are Blind
- 12/11 Integrating Low Tech and Switch Activities Into the Classroom
- 1/15 What are Talking Books and How do my Students Use Them
- 2/19 Let's Create Switch-Accessible Toys
- 3/5 Integrating Note Takers Into the General Ed Curriculum
- 4/16 Routines and Technology: Activities to Make it Work
- 5/7 Matching Technology to the Student

Math Distance Ed Presentations for 2002-2003

- 12/4 Consumer Math
- 1/22 Using Tangibles in Middle School Math
- 2/26 Preparing Nemeth With the Scientific Notebook
- 3/26 Elementary Math

Exact times have not yet been determined but all presentations will be in the afternoon. Watch <www.tsbvi.edu> for further information, or contact Jim Durkel at: <JimDurkel@tsbvi.edu> or (512) 206-9270.

TSBVI Short-Term Programs 2002-2003

Special Programs were developed to serve academic students from Texas who can benefit from a short period of intensive instruction in some area of the expanded core curriculum for visually impaired students. Referrals must come from the local school district (usually the VI teacher). Interested parents should confer with their school district about objectives for their child, and work together to make a referral.

Fall Semester 2002

- Dec. 1-6 Math (adapted tools & technology)
- Dec. 1-6 Practical Academics (students below grade level)
- *Dec. 12-15 Middle School Holiday Gift Making

Spring Semester 2003

- Jan. 12-17 High School IEP #2 (same as above)
- *Jan. 23-26 Low Vision Weekend (modifications & adaptations)
- Feb.9-14 Middle School IEP #2 (same as above)
- *Feb. 20-23 Teen Getaway (social enrichment)
- Mar.23-28 Secondary IEP #2 (same as above)
- *Apr. 5-8 A Capitol Experience (visit & learn about legislature)
- Apr.13-17 Elementary IEP #2 (same as above)
- *May 1-4 Elementary Austin Experience (social enrichment)

* Asterisks mark Thursday - Sunday events.
Contact: Dr. Lauren Newton, principal (512) 206 - 9119 or <newtonl@tsbvi.edu>

SEE/HEAR

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The audio version of *SEE/HEAR* is provided by
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**If you no longer wish to receive this newsletter,
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or e-mail her at BethRees@tsbvi.edu.**



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